

Joining the Dots for End-of-Life and the Mental Capacity Act

After having been involved with, from my former family-carer position, discussions about End-of-Life (EoL) Behaviour for over a decade, I have come to the conclusion that we need an easy-to-grasp way of describing the Mental Capacity Act (MCA). And I do not mean a slightly-modified MCA Code of Practice: I mean a simple, but fundamentally correct, way of expressing the meaning of the MCA, such that people who are not ‘MCA nerds’ can ‘get the purpose and point of’ the Act.

I will explain how I myself think of the MCA, having read it quite early during my ‘journey’ and with the benefit of what I have learnt since 2009 when my journey began: I will leave readers, to decide if what I write makes sense, and would be useful.

I will not be covering the aspect of the MCA which describes ‘detention’ - what was called Deprivation of Liberty Safeguards, and in future will be called Liberty Protection Safeguards. But I will mention something about DoLS/LPS, when compared to Best Interests (which is in essence what I will be writing about). The Act’s description of Best Interests (in section 4 of the Act), if we were considering road safety, would I think come across as ‘you must consider the situation, and not drive too quickly for safety’. Whereas in the same context, DoLS/LPS would come across as ‘setting specific maximum speed limits for every particular road’. I consider that the MCA’s description of Best Interests is largely ‘about principles and objectives’ - whereas, I think inevitably, DoLS/LPS is much more ‘about defined process’.

I am including references and when possible web-links to them, and there will be quite a lot of them. But I would suggest that readers, at least initially, read without going to the references. My reason, is that too many references can be distracting ‘from the thrust’: and, I think that many of the things I will be writing are ‘obvious’. I would prefer readers to read, and to think ‘does that seem intuitively correct?’, when reading the earlier part of this piece: and to follow the references provided, after having thought.

Over the years, I have discussed the MCA with doctors, paramedics, nurses, lawyers and to a lesser extent with patients and the relatives who have cared for loved-ones. I have even co-authored a paper in the Journal of Medical Ethics with a Paramedic, Hospital Doctor, and Barrister (ref 1).

Ref 1 <https://jme.bmj.com/content/early/2020/12/02/medethics-2020-106490>

If the ‘dots’ of my title are things such as information, the law, certainty and uncertainty, etc, then I can state that different people, and different groups of people tend to ‘join the dots differently’. And, often different people have different dots to start with. So, the pictures formed when different people join-the-dots for the MCA look different – my point, is that to make genuine progress, we need to all see very-much the same picture of the MCA when we join the dots.

Some ‘apparent’ assumptions often, and incorrectly, made about the MCA

There are certain things, which seem to be ‘taken for granted’ - but which are not in fact true. Notably the following:

1) It is often implied that only clinicians will be providing treatment – this isn’t true.

For example, cardiopulmonary resuscitation (CPR) is taught as first aid, so CPR could in many cases be attempted by relatives, friends and family-carers in the community, as well as by clinicians in hospital [and elsewhere] (ref 2).

And, it is possible when a person is living with dementia, that a GP might consider the prescription and administration of a tablet would be in the patient’s best interests – but it might fall to the person’s partner to actually administer the tablet, and the partner might consider that administering the tablet would not be in their loved-one’s best interests. So, in this situation, the problem is that there are two people involved in ‘provision of’ the treatment, and there is not ‘a hierarchy’ between them (refs 3 & 4).

Ref 2 <https://blogs.bmj.com/medical-ethics/2021/02/21/is-there-only-one-mental-capacity-act-or-are-there-two/>

Ref 3 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-PDF-contains-my-Anne-David-and-Dr-Jones-scenario-it-poses-the-question-what-is-the-meaning-of-shared-decision-making-for-EoL-at-home/947/>

Ref 4 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-Anne-David-and-Dr-Jones-scenario-who-is-deciding-what-in-this-scenario-/913/>

2) Except for a limited situation involving life-sustaining treatments, we do not really understand what MCA Best Interests is.

Section 4 of the Act, which ‘describes’ best interests, **only tells us what must be considered** when making a best-interests determination – and, unless section 4(5) applies (section 4(5) applies if the treatment is life-sustaining) we do not really know how we get from what we should consider, to a best-interests conclusion. What is clear, is that we need an understanding of both clinical things (available treatments, their prognoses, etc) AND ALSO of ‘the person/patient as an individual’ to arrive at a ‘deeply-considered’ best-interests determination. Which implies that we need clinicians and family and friends (‘those close to the patient’) **to be working together** within the best-interests ‘process’.

3) The MCA does not ‘provide an authority to treat’ - it provides a legal defence.

I have seen Consultant Doctors, write that the MCA gives them ‘the authority (or ‘power’) to act’ when a patient is mentally-incapable. This is untrue, and if that is how you think of what the Act does, it then leads to very incorrect thinking about ‘the MCA and authority’.

The MCA, provides anyone who can reasonably claim to have ‘satisfied’ section 4(9) {while not breaching sections 6(6) and 6(7) should those apply} to claim what amounts to a legal defence against accusations of intervening without consent, or of failing to intervene when an intervention would have been possible.

There is what could reasonably be described as ‘legal authority over best-interests’ within the MCA, but it is **not** given to doctors. And it is **not** given to relatives, family-carers, ‘next of kin’ (which is a concept not present within the MCA as it happens), or to anyone else except for Welfare Attorneys and Court Deputies. **Only attorneys and deputies are ‘given authority’ with respect to Best Interests by the Act:** that authority is given by section 6(6). Senior clinicians can potentially be given a sort of ‘pseudo-legal’ authority over other clinicians, by means of section 42 of the MCA and section 5.31 of the [original] Code of Practice. But section 42 is very ‘messy’ in practical terms, when we think about that ‘authority’ - it depends on what exactly exists within the ‘professional guidance’ of different professions. And section 42 does not allow for clinicians to exercise ‘authority’ over relatives, or vice versa.

This is connected to a little-understood [and as it happens I consider unnecessary and deeply unhelpful] ‘legal point’ about who can make decisions under the MCA – the

answer being only Judges, Welfare Attorneys and Court Deputies. I will discuss this issue later, only adding here that in principle anyone can make a best-interests determination which is satisfactory in the context of section 4, and which therefore makes the legal defences within section 5 available to the person who ‘acted in the incapacitous person’s best interests’.

What the MCA seemed to be saying when I first read the Act

When I read through the MCA (the Act) in 2009, my first thought having got to the end was ‘so how do I actually decide what is in a person’s best interests?’. So I read it again, and realised the answer to that is not present in the Act.

The other things I was struck by, included that mental capacity is assumed present – so it is the lack of capacity which must be asserted and proven:

1(2) A person must be assumed to have capacity unless it is established that he lacks capacity.

Section 2 of the Act, is if you think from the perspective of a family-carer, problematic in ways which it would be distracting to discuss at this point (I will discuss this later), but clearly if a law seeks to distinguish between mental capacity and mental incapacity some sort of definition of the two situations is necessary. So I tend to think of 2(1) as a statement of ‘the obvious’, and not in fact informative.

Section 3, contains 3(1) which is:

3(1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

(a) to understand the information relevant to the decision,

(b) to retain that information,

(c) to use or weigh that information as part of the process of making the decision, or

(d) to communicate his decision (whether by talking, using sign language or any other means).

Authors often describe 3(1) as a **test** of capacity – in fact, it is a **description** of how a capacitous person decides to accept or refuse an offered treatment (or any other offered choice). The problem, is that while (d) is physically-observable, and (a) and

(b) are reasonably easy to confirm and that confirmation seems uncontroversial, whatever (c) involves it is arguably ‘a private matter’. So, while it is easy to see that a doctor might want to understand (c), it is not obvious that a patient is required to explain ‘how I arrived at my decision’. For a medical treatment, 3(1) describes what is usually called Informed Consent [or, if the patient refuses, what I call Considered Refusal]. And informed consent only requires that the patient understands the consequences of accepting or refusing an offered treatment – it does not require the clinician to understand the details of (c). Obviously a patient can try to explain ‘why I decided as I did’ **if the patient wants to do that**.

The GMC has described Informed Consent in these terms, in its ‘Treatment and care towards the end of life: good practice in decision making {May 2010}’ as follows:

14 If a patient has capacity to make a decision for themselves, this is the decision-making model that applies:

(a) The doctor and patient make an assessment of the patient’s condition, taking into account the patient’s medical history, views, experience and knowledge.

(b) The doctor uses specialist knowledge and experience and clinical judgement, and the patient’s views and understanding of their condition, to identify which investigations or treatments are clinically appropriate and likely to result in overall benefit for the patient. The doctor explains the options to the patient, setting out the potential benefits, burdens and risks of each option. The doctor may recommend a particular option which they believe to be best for the patient, but they must not put pressure on the patient to accept their advice.

(c) The patient weighs up the potential benefits, burdens and risks of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which. They also have the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all.

(d) If the patient asks for a treatment that the doctor considers would not be clinically appropriate for them, the doctor should discuss the issues with the patient and explore the reasons for their request. If, after discussion, the doctor still considers that the treatment would not be clinically appropriate to the patient, they do not have to provide the treatment. They should explain their reasons to the patient and explain any other options that are available, including the option to seek a

second opinion or access legal representation.

The GMC's section 14(c), corresponds to the MCA's section 3(1)(c) – but the GMC's description of 'how a capacitous patient actually decides' is very much clearer, and if 'a patient has the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all' then in some situations a patient would not be able to explain 'how I decided' (in the situation of the patient 'deciding for no reason at all': how, if you decided 'for no reason', could you give your reason?!). In passing, I feel sure the 'for no reason at all' wording was taken by the GMC from a court ruling, but I am not sure which Judge stated that (I think I came across the wording in a court ruling, but I did not make a note of the ruling).

When I read on to section 4 of the MCA, which describes Best Interests, it is interesting that section 4(6) requires a person making a best-interests determination to try and work out 'how the patient would have decided if the patient were capacitous' - section 4(6)(b) is pointing at exactly the 'internal thinking' of MCA 3(1)(c) and the GMC's 14(c), which as I have pointed out the patient can legitimately refuse to elaborate on while still capacitous:

4(6) He must consider, so far as is reasonably ascertainable—

(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.

Another striking point about section 4, is that it appears that provided the person making a best-interests determination has done so 'in compliance with' section 4, any person can make a best-interests determination about anything:

4(9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.

It seems to me, that everyone except for judges, is described by 'a person other than the court'.

Section 4(11)(b) - "*Relevant circumstances*" are those— *(a) of which the person making the determination is aware, and (b) which it would be reasonable to regard as relevant* – is to my mind potentially unclear: I consider, to be consistent with the

thrust of section 4, 4(11)(b) must mean ‘and which the incapacitous person would regard as relevant’ (see footnote). With that interpretation, nothing in section 4 points to any ‘beliefs or ‘values’” except for those of the incapacitous person – which makes sense to me, because if the MCA is the guide to how an incapacitous person should be treated, then the ‘values and beliefs of’ whoever happens to be making the best-interests determination should be irrelevant. What I took from section 4, includes ‘in principle, a best-interests determination should not depend on who is making the determination’ (it clearly is affected by how much information and understanding the person making the determination possesses – but, it should not be influenced by things such as the religious beliefs of the person making the determination).

Judges seem to agree with me on this point – for example, in the ‘Briggs’ ruling (ref 5), Mr Justice Charles wrote (in his REASONING section):

62. But, in my view when the magnetic factors engage the fundamental and intensely personal competing principles of the sanctity of life and of self-determination which an individual with capacity can lawfully resolve and determine by giving or refusing consent to available treatment regimes:

i) the decision maker and so a judge must be wary of giving weight to what he thinks is prudent or what he would want for himself or his family, or what he thinks most people would or should want, and

ii) if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life.

Ref 5 <https://www.judiciary.gov.uk/wp-content/uploads/2016/12/l-briggs-v-p-briggs-others.pdf>

In passing I will point out, that if a potentially life-sustaining intervention is being considered, Mr Justice Charles has ‘effectively’ stated that Best Interests becomes Substituted Judgement in situations such as ‘coma-from-capacity’ and, using the same reasoning, ‘cardiopulmonary-arrest-from-capacity’. I will return to this later, when cardiopulmonary resuscitation (CPR) is being discussed, and here I will comment that the conclusion of Mr Justice Charles (62(ii)) seems to be an inevitable consequence of section 4(5) of the MCA.

Footnote. I really mean, that relevant must mean ‘relevant to the patient as an individual’. Whether an incapacitous person actually could consider relevance is a different issue – clearly someone in a coma couldn’t. The essential point, is that the ‘relevance’ must stem from the incapacitous person, and must not be something external which is imposed on the incapacitous person. See also the ‘Briggs’ ruling, where it clearly would have been things Mr Briggs would have considered relevant when he was previously capacitous.

What the MCA seems to be saying as I currently understand it

It can become very ‘intricate’ when the fine-detail of the MCA is discussed, but the way I see the thrust of the Act having thought about it for a decade, is as follows. The way I ‘see’ the Act, is not identical to how many doctors and lawyers would ‘see’ it: in large part, our differences can be explained by ‘2am in dad’s bedroom, 10pm in a hospital ward, and 2pm in a court are different situations – and while we have only one MCA, the way the Act ‘operates’ will necessarily have to reflect these differences’.

In my opinion, the thrust of the MCA is (ignoring fine detail – for example, a person can appoint more than one welfare attorney):

- a) Unless ‘proven’ to lack mental capacity, people/patients make their own decisions after having been informed of the consequences, and these capacitous individuals can be ‘self destructive’;
- b) While capacitous, a person can ‘project forwards into anticipated incapacity’ a refusal of a medical treatment by means of an Advance Decision;
- c) While capacitous, a person can [with official approval] appoint a [Health and] Welfare Attorney who should ‘control’ best-interests decision-making;
- d) It immediately follows, from the fact that most welfare attorneys are likely to be relatives or friends of the ‘patient/donor’, that **best-interests decisions are NOT ‘clinical decisions’** - unless the term ‘clinical decision’ does not imply ‘a decision requiring clinical expertise’;
- e) In principle (and setting aside the fact that sometimes there might be more than one equally good decision) in any given situation there should be ‘a best best-interests decision’ - and the objective of the Act, must surely be for the best-interests decision-maker, whoever that is, to arrive at that ‘best best-interests decision’.

The autonomy of capacitous patients, my a) above, is probably best-illustrated by something Justice Sir Mark Hedley told a newspaper (which I summarised in a BMJ rapid response – Sir Mark was the out-of-hours Court of Protection Judge and the hospital doctors phoned him):

This does equate to, expressed 'simply', 'a mentally-capable person cannot be 'safeguarded' against her wish': and I suspect that there is a powerful tension between that legal position and 'various expectations placed on professionals'. There is, for example, a 'sort of expectation' among public, media and politicians that 'suicide should be prevented': but Sir Mark Hedley has explained that a mentally-capable person part-way through a suicide attempt, cannot legally be treated without consent (ref 1). Sir Mark Hedley's words were admirably clear: "I decided at 10pm that a suicidal man with mental health problems could be allowed to die of an overdose rather than order doctors to pump his stomach ... I decided he had capacity [to refuse treatment], so he died that night. That's exactly what he wanted to do". This is not a judge saying 'the patient is autonomous unless his decision distresses people'.

Addressing a less-extreme situation than that of a suicidal capacitous patient, the court ruling which drove-home the autonomy of patients and the requirement for 'genuine informed consent' was the Montgomery ruling:

Ref 7 <https://www.supremecourt.uk/cases/docs/uksc-2013-0136-judgment.pdf>

Lady Hale, right at the end of 'Montgomery', told us something which people who read court rulings and quote particular sentences, to use my phrase 'as if the wording of the judge contains 'magic'', really should take this on board (my added bolds):

*117. These additional observations, dealing with the specific example of pregnancy and childbirth, are merely a footnote to the comprehensive judgment of Lord Kerr and Lord Reed, **with which I entirely agree. Were anyone to be able to detect a difference between us, I would instantly defer to their way of putting it. I would allow this appeal.***

In their rulings, judges are often trying to explain a concept: they are forced to use words, but as Lady Hale makes clear expressing a concept in words is often tricky.

My c) above, is interesting, in that a welfare attorney who is chosen by the person/patient **can** be given authority over life-sustaining treatments – but a court deputy, appointed by a court after the person/patient has already lost capacity, **cannot** be given authority over life-sustaining treatments. To me, this is part of the MCA's empowerment of capacitous individuals.

My d) above, is something which really annoys me. I keep reading sentences such as ‘DNACPR is a medical decision’ or ‘DNACPR is a clinical decision’ and **when I read those phrases** they come across as ‘a DNACPR decision can only be made by a clinician’. This simply cannot be true – that immediately follows, if welfare attorneys who are not clinically-trained, can be given the authority of section 6(6) by the MCA.

I have written about this many times, and a good piece to read would be:

Ref 8 <https://www.dignityincare.org.uk/Discuss-and-debate/download/435/>

My e) above, when considered in combination with the fact that clinicians, relatives and friends can in theory all [and **individually**] arrive at legally-defensible best-interests decisions, leads me to write something which can be found in the first of the PDFs which can be downloaded from my thread about ReSPECT:

Ref 9 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/An-issue-with-ReSPECT-which-I-will-be-pointing-out-to-the-Public-Guardian/960/>

*It is surely logically the case, that **in the absence of an attorney or deputy with authority** over best-interests decision-making conferred by 6(6), after the discussions between the various parties involved in the ongoing care of an already incapacitous person, **there will often be a group of people** – loosely, I’ll here write ‘a group composed of family and clinicians’ - **who can each individually say** ‘my decision would be ‘whatever’ - and I think I can claim to have made that decision in compliance with section 4(9)’.*

That situation is only clear, if all of that group believe the same recommendation would be in the patient’s best interests: but in such a situation, logically the most ‘compelling and legally defensible’ thing on the form, which would then be read by someone such as a 999 paramedic, would be along the lines of:

‘We the undersigned, have discussed whether it is likely to be in this patient’s best-interests for CPR to be attempted, and we hereby sign to confirm that we all believe that DNACPR is in the patient’s best interests – we also confirm that to the best of our knowledge, no sufficiently well-informed person has expressed the opinion that attempted CPR would be in the patient’s best interests’

SIGNED BY EVERYONE – family and clinicians.

‘MCA nerds’ will appreciate, that in effect what I have written is a documentation of a situation when ‘everyone agrees about the best-interests decision which has been recorded – and nobody is contesting the decision (i.e. nobody is asking for a court ruling to settle a dispute)’. With confirmation of that, by means of signatures from both ‘sides’ - at least one signature, if possible, from the ‘family and friends side’ in addition to a signature from the clinical team’.

Ben Troke, a solicitor, has written a book ‘A Practical Guide to the Law of Medical Treatment Decisions’ (Paperback: 978-1-912687-89-3 published 2020 by Law Brief Publishing).

In Ben’s book, he points out on pages 106/107 that if there is a substantial dispute between clinicians and relatives about what treatment would be in the patient’s best interests, it must be referred to the Court of Protection. Technically, I think Ben’s ‘must’ is a real-world description of what is a ‘can’: anyone who objects to a best-interests determination, can apply to the Court of Protection for a ruling, so telling clinicians that ‘a serious dispute must go to court’ seems reasonable as real-world advice [especially as professional guidance probably points that way as well].

Ben’s point – which I agree with – is that in a sense it doesn’t matter if we consider that the clinicians make the best-interests determination, or if we believe the family and friends make the best-interests determination: because any major dispute should be resolved by the Court of Protection, and [**as I repeatedly write!**] if everyone agrees then do not make assertions that a particular individual ‘**made the best-interests determination**’.

I feel so strongly about this, that I will state it in a different – and large – font.

If clinicians and family/friends are in agreement about what is in the patient’s best interests, then DO NOT say ‘the relatives agreed with the clinician’s decision’, and DO NOT say ‘the clinicians agreed with the family’s decision’.

Just say ‘Everyone put their heads together, and everyone agreed about what would be in the patient’s best interests’.

In passing, I will point out that in the same section of Ben’s book he makes the point that it is a useful approach to ask ‘who would need to rely on the best-interests defence?’. And Ben uses the example of a lower limb amputation – clearly the surgeon needs that legal defence. As I pointed out very early in this piece, on page 2

in my 1), for cardiopulmonary resuscitation (CPR) the situation is different – both clinicians and also many laypeople could perform CPR. In passing, as the following reference explains, it is not entirely clear whether many relatives actually need a legal defence if they decide to not attempt CPR (they probably don't) – if anyone wishes to 'jump ahead' then my recent piece about this is (ref 10) at:

Ref 10 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/DNACPR-at-Home-and-a-Twitter-thread-what-is-the-legal-situation-for-relatives/1110/>

In his book, Ben Troke also starts a discussion of what MCA Best Interests **is**, by listing on pages 107/8 a few things which Best Interests **is not** – two of these things, being 'not whatever "next of kin" or family want' and 'not the safest option'.

It is, for the MCA, I think easier to describe what best interests isn't, than to describe what best interests is. However, perhaps foolishly a few years ago I pondered in an e-mail whether MCA best interests could be correctly described in one or two sentences: then, I realised I had to have a go at answering my own question!

The answer I came up with, and my arguments, can be found in ref 11:

Ref 11 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/MCA-Best-Interests-compressed-to-a-single-sentence-an-ansatz/972/>

I came up with a single sentence, which I believe correctly describes the objective of a best-interests determination:

The objective is to make the best-interests decision which would result in the most satisfactory future when considered from the perspective of the incapacitous person as an individual.

Now, the reader might ask 'why do we need such a sentence?'. My answer is as follows.

Suppose, dad is in hospital after some sort of accident or sudden medical crisis, and dad is very clearly mentally-incapable – perhaps 'deeply unconscious'. After a few days a hospital doctor phones mum, and says 'Can you and your two adult sons come in for a meeting tomorrow?'. Mum asks what the purpose of the meeting will be. The doctor might answer 'So you can help us [doctors] to decide what happens next' - I

regard that as the WRONG answer. An answer which I consider to be correct, is ‘So we can see if everyone agrees about what should happen next [to your husband]’. This is clearly ‘a best-interests meetings’. Suppose the doctor actually says ‘We need to work out what is in dad’s best interests’. That answer is correct; but unsatisfactory, for this reason. Most relatives, will have absolutely no idea what ‘best interests’ means. So, if mum says ‘What does best interests mean? To get our thoughts in order, we need to understand the purpose of the meeting, before we come to it’, then **it isn’t very helpful, for the doctor to say ‘Best Interests is described in the Mental Capacity Act – you need to read the MCA before you come in tomorrow’.**

Various people comment on my one-sentence-description of the purpose of a best-interests determination in ref 11, and the comment from Dr Kathryn Mannix starts with this:

‘I like your sentence because it helps decision-makers and those participating in a decision-making process to be clear about the task’.

As Ben Troke points out in his book, and as I point out in many of my pieces including in ref 12, best interests does not mean ‘what the patient [if capacitous] would have decided’ in most situations. But, it does amount to that in certain situations involving life-sustaining treatments – see what Mr Justice Charles wrote (page 7). For situations comparable to that of ‘Briggs’, Best Interests does effectively become Substituted Judgement:

Ref 12 <https://www.dignityincare.org.uk/Discuss-and-debate/download/353/>

See also my discussion of whether a DNACPR decision can be ‘recorded in advance’ in ref 8. In ‘Briggs-type’ situations, best interests becomes this, to use my own words:

The Briggs Ruling applied to CPR

In the Briggs case, the patient had gone from being capacitous to long-term comatose very quickly, and the judge had to decide if it would be in the patient’s best interests to withdraw the CANH which was keeping him alive. The judge in effect decided that in such a situation, the MCA’s Best Interests becomes a version of Substituted Judgement, which amounts to, using my words here:

If the decision-maker is satisfied to a sufficient degree of certainty that the patient would have refused the intervention ‘had the patient been in the same situation but capacitous’, then the intervention should be withdrawn or withheld,

and,

If the decision the patient would have made is not understood with sufficient certainty, then the treatment is continued or applied in an attempt to preserve the patient's life (and, of course, if it is believed that the patient would have wanted the treatment if the patient were capacitous to decide, then the treatment is also continued or applied).

I will add, that when discussing this with a lawyer and a paramedic, we found it very difficult to decide how to be clearer about 'sufficient certainty' as I have written above, or '*if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life*' as Mr Justice Charles put it.

Most best-interests determinations will be made on balance of probability (if there are only two options, then whichever seems better will be chosen, even if only slightly better) – but, if you were only '51% certain' that the patient would have refused a life-sustaining intervention, would you remove or withhold it? I think not. And when phrases such as 'sure the patient would have refused' or 'certain' were suggested, I objected 'but to me, with science degrees, sure and certain both mean '100%' sure'. I think, the best 'lay' phrase is probably '... convinced that the patient would have refused the treatment'.

A little about how judges and lawyers argue

I have read various court rulings, and I must admit that quite often 'the line of reasoning' seems rather dubious to me. I think Mr Justice Charles in Briggs, arrived at the correct conclusion and stated the correct justification – but, he seemed to detour unnecessarily around several back alleys, and to waste time in doing that.

Mr Justice Charles, spent a lot of time 'proving that as a Judge he could make a best-interests decision that life-sustaining CANH should be withdrawn from Mr Briggs'. And, I think he could have proved the point much more briefly.

I will avoid investigating a 'bit of weirdness' around the word 'decision' and the use of 'consent' and 'refuse' in the MCA here (I will return to this), but I am aware of an issue with this.

In section 16 of ‘OVERVIEW’ Mr Justice Charles is clear on something which you might ‘miss’ when reading some court rulings – in a nutshell, when a law is passed (a Statute) then the new law replaces earlier case law. Only if the new Act is either internally-inconsistent or ‘fails to cover something’ do judges try to ‘change’ [or ‘add to’] a statute – hence:

(16) It is the application of the MCA, rather than the common law and inherent jurisdiction set out in the earlier cases that matters. However, the earlier cases remain relevant because they provide useful analyses of the relevant issues and form a central part of the background to the recommendations of the Law Commission on which the MCA was based and so to the MCA.

Mr Justice Charles then goes on to discuss various other cases, but more to the point he also shows in paragraph 18 of ‘REASONING’ section 11 of the MCA.

Now, section 6 of the MCA is framed in terms of best interests, whereas (and this is something I find both unnecessary and also deeply unhelpful!) section 11 is framed in terms of consent and refusal, but suffice it to say that everybody agrees that a welfare attorney can be given legal authority over best-interests determinations involving life-sustaining interventions. The clearest wording is in my opinion in section 7.29 of the original Code of Practice:

7.29 Attorneys must always follow the Act’s principles and make decisions in the donor’s best interests. If healthcare staff disagree with the attorney’s assessment of best interests, they should discuss the case with other medical experts and/or get a formal second opinion. Then they should discuss the matter further with the attorney. If they cannot settle the disagreement, they can apply to the Court of Protection (see paragraphs 7.45–7.49 below). While the court is coming to a decision, healthcare staff can give life-sustaining treatment to prolong the donor’s life or stop their condition getting worse.

But, we should argue from the Act itself, so we need to argue from sections 6(6) and 6(7), which appear in my ‘copy’ of the MCA as:

6(6) Section 5 does not authorise a person to do an act which conflicts with a decision made, within the scope of his authority and in accordance with this Part, by

-
- (a) a donee of a lasting power of attorney granted by P, or*
 - (b) a deputy appointed for P by the court.*

*6(7) But nothing in subsection (6) stops a person—
(a) providing life-sustaining treatment, or
(b) doing any act which he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court.*

In passing, I will point out that [as the Code seems to believe] I consider the 'while a decision is sought from a court' must apply to both 6(7)(a) and 6(7)(b), even though it appears to only apply to 6(7)(b) in the above – it should be:

*6(7) But nothing in subsection (6) stops a person—
(a) providing life-sustaining treatment, or
(b) doing any act which he reasonably believes to be necessary to prevent a serious deterioration in P's condition,*

while a decision as respects any relevant issue is sought from the court.

Now, I think most lay people, would be bemused by the suggestion that a Judge could not make a best-interests decision that CANH should be withdrawn, when section 11 makes it clear that some welfare attorneys can refuse consent for the application or continuation of CANH. I think most non-legal people would just say 'it would be absurd, if a welfare attorney can forbid CANH, if a Judge couldn't forbid CANH!'.

However – I wouldn't have expected Mr Justice Charles to use that argument.

But – he could have used the following analysis, **and saved a lot of discussion**:

Suppose Mrs Briggs had been her husband's welfare attorney, and she had been given authority over life-sustaining treatments. If Mrs Briggs had said 'I consider it to be in my husband's best interests for CANH to be withdrawn' then either the clinicians would have had to withdraw CANH, or they could continue the CANH while asking for a ruling from a Judge. If a judge could never rule that withdrawal of CANH was in a patient's best interests, then all appeals for rulings from the Court of Protection would have to result in the judge ruling that CANH must be continued. Which is an obvious internal paradox: section 6(6) 'is not purposeful', if whenever an attorney tells doctors to withdraw or withhold a life-sustaining treatment, the doctors can appeal to a court and the judge has no choice but to say 'the life-sustaining treatment must continue'.

I will now return to this 'decision/consent' issue.

When you read the MCA from the start, it is framed in terms of best interests: all decisions must be made in an incapacitous patient's best interests, although rather

mysteriously section 4 doesn't use the term 'decision' - it uses the term 'determination'. Suddenly, and for no obvious reason at all, in section 11 we are told that welfare attorneys and court deputies can consent to, or refuse, an offered treatment. This always looked like a drafting error to me – because like everyone else, attorneys and deputies are required to make decisions in the patient's best interests.

If I were a welfare attorney, **I would consider the donor's best interests in the knowledge** that a treatment was being offered – then I would not 'consent' or 'refuse', I would say either 'I consider application of the treatment is in his best interests' or 'application of the treatment is not in his best interests'.

Historically, a judge stated that nobody can consent to treatment on behalf of an incapacitous patient.

The MCA could, so far as I can see, have been written entirely in terms of best interests, and a hierarchy among best-interests decision-makers: basically it could have said that section 4 described best-interests decision-making, with sections 6(6) and 6(7), and 20(4) describes what I shall call a 'hierarchy' within best-interests decision-makers.

However, I was informed by a lawyer about a year ago, that the legal situation is different (and, to my mind, bonkers!). It seems, the MCA has been framed with the concept that only deputies, attorneys and judges can make a best-interests DECISION. Everyone else – so doctors, family-carers, 999 paramedics, etc – can only make a best-interests DETERMINATION. Despite this, ANYONE who can claim to have applied section 4 correctly, can then claim the legal protections described in section 5 of the Act.

Almost nobody I know, understood this [weird] legal point: a doctor, when I asked, replied that she had thought doctors made best-interests decisions, and someone else who has been very involved with the MCA for at least a decade, commented during a phonecall when I explained this '... ah – so THAT is why 'determination' appears all over the place!'. I will also add, that the Code of Practice uses the word 'decision' in many places, when it seems it should be using 'determination'.

All I can really say, is to repeat my annoyance with this: I can see no reason at all, why having described things in terms of best interests in section 4, etc, the Act then introduced this complexity of 'only judges, welfare attorneys and court deputies can make decisions under the Act'.

I will throw in, that in lay language it is likely that as part of making a decision, a person will probably determine various things – and, that before I had been told of this legal situation, this section of the Act seemed obvious to me:

1(5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

I took the above to mean that ‘an act done’ meant something physically observable – the attempting of CPR, the administration of an injection. And that ‘or decision made’, covered non-intervention - ‘it was decided to not attempt CPR, or to not give an injection’. The logic being that it is clear when something is done, and we can assume there was a decision to do it – whereas if something isn’t done, it is not so obvious whether there was a decision to not do it.

But – now – I read 1(5) with an understanding that ‘a decision made’ in 1(5) can only apply if a judge, attorney or deputy is involved. UTTER MADNESS! I will add, in passing, that it isn’t obvious to me where the Act says that a doctor can appeal to a court if an attorney frames a response in terms of a refusal of consent: if an attorney says ‘continued CANH would not be in the patient’s best interests’ then section 6(7) allows for an appeal to the court – but if, using the wording of section 11, an attorney says ‘I do not consent to CANH’ then I haven’t spotted where the Act allows for that to be challenged? Especially as there is not any available challenge when a capacitous patient says ‘I do not consent’ (so we should have kept consent and refusal to describe the situation of capacity, and kept best interests for use during the situation of incapacity, in my opinion).

Jane, Mary, Tony and their Advance Decisions

Advance Decisions are described in sections 24-26 of the Act, and the section which is most useful for ‘revealing what an ADRT is’ is section 25(4):

25(4) An advance decision is not applicable to the treatment in question if—
(a) that treatment is not the treatment specified in the advance decision,
(b) any circumstances specified in the advance decision are absent, or
(c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

Of passing interest here – because in reality ‘everyone seems to ignore this ‘as a technicality’’ - it appears that an ADRT can only be phrased as ‘I refuse ‘specified’ treatment if ‘qualifying circumstance/s’. From 25(4)(b) it looks as if you can write ‘I refuse CPR’ and that would mean ‘I refuse CPR in all situations’. Or you might write ‘I refuse CPR if I am in my own home’ which would allow CPR anywhere else, for example if you were in hospital. But ‘I refuse ‘treatment’ unless ‘circumstance’’ doesn’t fit with 25(4)(b).

The core objective of an ADRT is, to my mind, revealed by 25(4)(c) – unless there is good reason to believe that the person had not considered the situation when making the ADRT, the ADRT should be accepted and followed. And even then, knowing the person had not considered something is not enough: to ‘refute’ the ADRT, we must have a reasonable belief that the person who made the ADRT did not know about something, and had he known about it he would have accepted the treatment.

Jane lives to be sporty and active, and one of her passions is rock climbing. Jane cannot conceive of being alive but bedbound, or even worse alive with brain-damage and being kept alive by clinically-assisted nutrition and hydration (CANH). So Jane wants to use an Advance Decision(ADRT) ‘to refuse such future outcomes’. In essence, Jane is worried that she might fall while rock climbing, and then end up in a situation she ‘dreads’. But, Jane cannot refuse a future situation using an ADRT – she can refuse treatments. It isn’t immediately obvious, what Jane should refuse: perhaps something such as ‘I refuse artificial life-support if it has already been in place for 7 days’ (then, if she hadn’t become capacitous after 7 days on life-support, the life-support would have to be removed). I’ll leave the reader to work out what Jane might write on her ADRT, and in passing I will point out that whatever her ADRT says, it is unlikely to prevent immediate treatment if she is found at the bottom of a cliff by 999 paramedics.

Mary, is very ethically-aware. Mary considers that a drug, Traficulivir, was developed as a consequence of ethically-unacceptable research. Mary wants to be treated if she needs to be treated, but she forbids the use of Traficulivir for any purpose at all. A simple ADRT saying ‘I forbid the use of Traficulivir to treat me, for any purpose whatever’ should work for Mary. NOTE: ‘Traficulivir’ is a fictional drug [I hope!].

Tony, is faced with a potential future which he wants to avoid. He doesn’t want to face ‘his prognosis’ if he can avoid it. So Tony writes an ADRT refusing CPR, if his heart has stopped beating for any reason. He wants to use the opportunity which a cardiopulmonary arrest would present, to avoid a future he prefers not to face. If Tony is 80 yrs old and frail, many people might easily understand this refusal. But Tony could be young, and ‘still ‘healthy’’ but with a horrible degenerative-prognosis hanging over him: when he writes an ADRT saying ‘I refuse CPR, and this refusal stands whatever caused my heart to stop beating’ he means exactly that.

In my experience, the clinically-authored material on ADRTs often says what amounts to ‘there might come a time, when your medical condition has deteriorated to a point when you might consider refusing CPR or other interventions’. Which is true, but not ‘necessary’ - you can decide to create an ADRT while you still seem to be ‘very healthy’. The point is – **it is your decision, and you decide what is relevant and important yourself.**

Best Interests and Clinical Uncertainty

The situations which I usually write about, involve CPR and complexity around ‘who can know what’, and they **could not** end up with a Court of Protection judge being asked to make a ruling. The cases which have similar legal principles to CPR, usually involve the continuation or withdrawal of CANH, for the simple reason that those cases **can** be considered by judges.

Judges can only make a ruling, which pertains to the particular case in front of them – a judge explains how the judge believes the law applies to the case being considered. Only very rarely, in my experience, do rulings include what might appear ‘in a text book’ - I really love Lady Hale’s ‘appendix to’ the Montgomery ruling, because it does look as she wanted to do a bit of ‘legal teaching’. Plus, it is a brilliant bit of writing.

In CANH cases, usually the judge will be trying to make a best-interests decision about the continuation or withdrawal of CANH or something similar. And often, a reader might gain the impression ‘that a best-interests decision cannot be made until the details of the patient’s medical condition, and the likely prognoses, have been well-understood’.

Put more concisely, it might be concluded from certain court cases ‘that before a best-interests decision/determination can be made, clinical certainty must be established’.

I cannot see, how that can be true.

One way of thinking about what Mr Justice Charles was doing in ‘Briggs’, is ‘Mr Justice Charles was trying to work out what Mr Briggs would have written in an ADRT applying to his situation, if while he had been capacitous Mr Briggs had thought about that future situation and decided to write an ADRT (including, of course, would Mr Briggs have decided to not write an ADRT because he wanted continued treatment)’. And it is perfectly possible, for a person to consider a situation when in the future he might be unconscious and the prognosis could be so uncertain that it could include both a complete recovery and also being permanently comatose. The uncertainty of the prognosis, does not prevent a person from creating an ADRT. As we can see from the stories of Jane and to a lesser-extent Tony on page 19, uncertainty-of-prognosis is something a person considers when creating an ADRT – and, indeed, uncertainty is something a patient should consider during ‘normal informed consent’.

What **is true**, is that when best interests is being considered and the prognosis is very unclear, it is harder for the best-interests decision-maker to be confident of what the patient would have decided. It isn’t that conceptually, a best-interests determination cannot be made until the clinical situation and prognosis is well-understood – the

problem, is simply that the more unclear the situation, the harder it is to convince oneself 'of what the patient would have wanted to happen'.

There was a case, when a judge said something to the effect of 'the court cannot accomplish for an incapacitous person, something that a capacitous person could not accomplish for himself'. In essence, I am suggesting that we can probably 'flip' that, and write 'a best-interests decision, should be able to accomplish for an incapacitous person, an outcome which while capacitous the person could have accomplished for himself'.

A Correct but 'Perverse' Legal Point

The lawyers of 39 Essex Chambers, have pointed out something which is logically true about the authority of a welfare attorney over best-interests decision-making – that the authority exists at the time a decision is being made. I have written about this (ref 13) and I dislike what those lawyers seem to then 'move on to' - I show part of ref 13 below:

Ref 13 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Is-the-power-of-a-Welfare-Attorney-LPA-largely-an-illusion-a-response-to-39-Essex-Chambers/1103/>

The NHS has recently updated its online information about CPR/DNACPR, and the lawyers of 39 Essex Chambers have commented on it in their 'Mental Capacity Report: The Wider Context', March 2021, Issue 112. The Essex Chambers writers, on page 3, suggest that a welfare attorney whose authority extends over CPR, can only make and express a DNACPR decision at the time the patient/donor is ACTUALLY IN cardiopulmonary arrest. I wish to comment on this suggestion/assertion.

I would absolutely agree that a best-interests determination should ideally be made at the time the treatment would be applied or withheld: that is a logical consequence of 'the decision should be up-to-date'. But the NHS [and in fact judges, notably in the context of 'future CPR' during 'coma' situations] does entangle future CPR/DNACPR within its Advance Care Planning. Exactly what this future-planning is in legal/technical terms - I prefer something like 'anticipatory best-interests decisions' whereas ReSPECT uses 'recommendations' (neither term is ideal: in essence, an informed person or group of people now, are trying to somehow 'project into the future' their understanding to less-informed clinicians who might subsequently become involved) - is very tricky to describe. Fortunately, I need not do that yet (although I will return to this word 'recommendations' later) because first I am going to point at 'something weird' within the Essex Chambers position.

Suppose the patient/donor has already lost mental capacity, having previously given a welfare attorney legal powers over best-interests decision-making about CPR/DNACPR. The reason the patient did that, is both simple and obvious: the patient wanted the decision about CPR to be made by his/her chosen attorney/s - NOT by doctors and other clinicians. If ACP and similar processes/documentation is to be used by the NHS to influence future CPR decision-making, then CLEARLY THE PATIENT WANTED THE ATTORNEY to 'control' such ACP etc: that is why you give your attorney powers over best-interests decisions. The 'ethos of' the MCA, seems to me to be that if I lose capacity, then my welfare attorney should be making any necessary best-interests decisions, AND ALSO by implication 'controlling any 'recommendations/documents" pertaining to [future] best-interests decisions which are being anticipated by means of documents.

I continue from the above, in my piece at ref 13, but if Essex Chambers are correct in how the physical presence or absence of a welfare attorney or court deputy should be reflected within NHS thinking and [ACP] documentation, we could end up with attorneys and deputies concluding 'so I must set-up a camp bed at the hospital patient's bedside, and stay there 24/7, or else I cannot make any necessary best-interests decisions as the patient wanted me to'.

We also, get to this (extracted from ref 13):

Consider a patient in a coma, in hospital, and an attorney who is at the patient's bedside, discussing a life-sustaining treatment such as CANH or artificial ventilation with the clinicians. The attorney tells the clinicians to withdraw the life-sustaining intervention: Essex Chambers do not appear to dispute that the attorney has the power/authority to do this. But, when we apply what Essex Chambers assert about CPR to this scenario, it seems that as soon as the attorney leaves the bedside/hospital, the hospital's clinicians (even the clinicians who the attorney was talking to face-to-face) can simply decide to reinstate the life-sustaining treatments. WITHOUT APPLYING FOR A COURT RULING. If this is how the Act works - then why does it say (section 6(7) and 7.29 in the Code) that clinicians can go against the attorney's decision, and try to keep the patient alive 'while a decision is sought from the court'? If simply waiting until an attorney is no longer physically present, is sufficient 'to remove the attorney's authority', then why bother to put section 6(7) in the Act at all?

The verbal refusal of CPR

The BMA, RCN and RC(UK) jointly-publish guidance about CPR, and in the 2007 version of the guidance (which it seems can no longer be found online – searching seems to only return more recent versions) the Main Messages section included:

If a patient with capacity refuses CPR, or a patient lacking capacity has a valid and applicable advance decision refusing CPR, this should be respected.

I consider that to be correct – provided we are considering a situation which is one involving what I describe as ‘ongoing contact’.

I have been really annoyed since about 2010, to discover that since then almost all CPR guidance does not state the above: more recent guidance says ‘a verbal refusal of CPR is not legally binding’ and ‘a valid and applicable advance decision refusing CPR is legally binding’.

I have been banging-away at this for years, and pages 26 to 33 in ref 14 discuss the verbal refusal of CPR:

Ref 14 <https://www.dignityincare.org.uk/Discuss-and-debate/download/317/>

I have also analysed this issue in a more-recent piece at:

Ref 15 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Can-a-verbal-refusal-of-CPR-be-legally-binding/1072/>

The problem is this: while a verbal refusal of CPR clearly cannot be a valid Advance Decision, it can nevertheless be ‘more legally binding’ than a valid written Advance Decision refusing CPR.

The correct way to think about this, is to consider how certain the listener is of the fact that the patient has refused CPR in the circumstances of the cardiopulmonary arrest.

If a hospital patient explains during a 30-minute conversation with a hospital doctor, that the patient would never want CPR, whatever the reason his heart had stopped beating, during the conversation the doctor can ask and exhaust all of the ‘... have you considered ...’ and ‘... but if [whatever], would you still refuse CPR’ questions. So, if at the end of that conversation, as the doctor turns to walk away from the bedside the patient suddenly arrests, **then the doctor has no thinking to do** – the doctor is as certain as it is ever possible to be, that the patient has forbidden CPR in the situation.

If we swap the hospital doctor for a GP, and the location to the patient’s home, and we have the same conversation at the end of which the two of them create a written Advance Decision refusing CPR, then what is the situation if a month later the patient walks in to the GP’s Surgery, and just after entering the GP’s office the patient arrests and collapses with his written ADRT in his hand? If the GP sees the written ADRT, does the GP know why the patient was holding it? Was the patient about to say ‘I’ve

changed my mind – I want to retract this ADRT’ or was the patient about to say ‘Are you sure that if I arrest at home, and my wife shows this to a 999 paramedic, it will stop the paramedic from attempting CPR?’.

The gap of a month, between the patient and GP creating the written ADRT, and the ADRT being read when the patient subsequently has a cardiopulmonary arrest, **introduces doubts which are not present in the verbal refusal in the hospital scenario**. And without the ARDT in the patient’s hand, the GP still cannot be certain whether the patient has changed his mind about CPR during the month since they last talked to each other.

Similarly, if a wife makes it very clear to her husband that she would never want CPR, because they are sharing a home the husband can reasonably assume ‘if she changes her mind, my wife will tell me’.

THE GREATER UNDERSTANDING MAKES A VERBAL REFUSAL [and no subsequent verbal retraction] THE MOST ‘LEGALLY BINDING’ OF ALL INSTRUCTIONS FROM THE PATIENT/PERSON.

If ‘technically’ a person should make a best-interests determination, but in reality the understanding of the person is such that ‘there is no determination to be performed – I am already absolutely sure of what I should do’, then there is not a best-interests determination being carried-out in any meaningful sense.

An issue with the so-called ‘diagnostic test’ of section 2

I mentioned on page 4, that from the perspective of a family-carer there is a problem introduced by section 2 of the ACT, and that I would discuss it later.

Section 3(1) of the Act, is often described as ‘the functional test’ of capacity. A lot of professional guidance, suggests that the first thing to do is to decide if there is a ‘disturbance of’ the mind: then, to move on to section 3. The question of whether the person does have a disturbance of the mind, is usually described as ‘the diagnostic test’.

The problem, is as follows. As a family-carer, it is clear that my loved-one makes his or her own decisions while capacitous; and, we know that capacity is both decision and time dependent – so, before I ‘invoke’ section 4, I must **at the time** persuade myself that my loved-one is lacking in capacity. I can ‘easily see’ certain things: for example, if a person is unconscious, absolutely intoxicated or is hallucinating. The way I see section 3(1), in the context of the reservations about 3(1)(c) which I have described earlier, is that I need to check that my loved-one understands the

consequences of a decision. I have in the past used a rather extreme example to illustrate this. If a person standing on top of a tall building says ‘I am going to jump off, and fly away’, then the person is probably mentally-incapable and probably not suicidal. But if a person standing on top of a tall building says ‘I am going to jump off, and fall to my death’ then the person could well be mentally-capable and also suicidal.

The problem, is that there is clearly a concept of there being some ‘mental illnesses’ which do not prevent a person from understanding the consequences of their decision, but despite that remove the person’s mental capacity. And as a layman – bearing in mind that capacity can fluctuate, and I am in theory required to consider capacity at the time I am wondering if I should invoke best interests – how can I decide if an illness is causing incapacity despite the person seeming to correctly understand the consequences of actions and decisions?

In passing, this also seems ‘very circular’: ‘I assert that you have an illness causing you to be mentally-incapable, even though it may appear as if you understand the consequences of your decisions’ looks rather ‘catch 22’.

As it happens, Mr Justice MacDonald seems to have had very similar issues to mine, in this court ruling:

Ref 16

<http://www.bailii.org/cgi-bin/markup.cgi?doc=/ew/cases/EWCOP/2015/80.html&query=court+and+of+and+Protection+and+Justice+and+MacDonald+and+sparkle&method=boolean>

Mr Justice MacDonald – see paragraph 93 – did not bother to try and apply the ‘diagnostic’ test of capacity, he simply decided what amounts to ‘she seemed capacitous according to section 3’:

92. Having regard to the foregoing matters in my judgment the Trust has not proved to the requisite standard that C is unable to use and weigh information relevant to the decision in question such that she lacks capacity to make that decision. In circumstances where the Trust concedes that C meets the other criteria comprising the ‘functional test’ I am satisfied that C is not a person unable to make a decision for herself for the purposes of s 3(1) and, accordingly, does not lack capacity to decide whether or not to accept dialysis.

93. Having found that C is not a person unable to make a decision for herself for the purposes of s 3(1) it is not necessary for me to go on to consider the so called ‘diagnostic test’. It is right to record that, as I observed at the conclusion of the hearing, had I been satisfied that C was unable to use and weigh information in the manner contended for by the Trust, I believe I would have had difficulty in deciding that this inability was, on the balance of probabilities, because of an impairment of, or a disturbance in the functioning of, the mind or brain. Whilst it is accepted by all

parties that C has an impairment of, or a disturbance in the functioning of, the mind or brain, the evidence as to the precise nature of that impairment or disturbance was far from conclusive. Further, and more importantly, with regard to the question of causation, and in particular whether what was being seen might be the operation of a personality disorder or simply the thought processes of a strong willed, stubborn individual with unpalatable and highly egocentric views the evidence was likewise somewhat equivocal. However, as I say, I need say no more about this in light of my conclusions as set out above.

Before I leave this court ruling, I will show paragraphs 97 and 98, which with tremendous clarity explain that capacitous patients make their own decisions, and also paragraph 99.

97. The decision C has reached to refuse dialysis can be characterised as an unwise one. That C considers that the prospect of growing old, the fear of living with fewer material possessions and the fear that she has lost, and will not regain, 'her sparkle' outweighs a prognosis that signals continued life will alarm and possibly horrify many, although I am satisfied that the ongoing discomfort of treatment, the fear of chronic illness and the fear of lifelong treatment and lifelong disability are factors that also weigh heavily in the balance for C. C's decision is certainly one that does not accord with the expectations of many in society. Indeed, others in society may consider C's decision to be unreasonable, illogical or even immoral within the context of the sanctity accorded to life by society in general. None of this however is evidence of a lack of capacity. The court being satisfied that, in accordance with the provisions of the Mental Capacity Act 2005, C has capacity to decide whether or not to accept treatment C is entitled to make her own decision on that question based on the things that are important to her, in keeping with her own personality and system of values and without conforming to society's expectation of what constitutes the 'normal' decision in this situation (if such a thing exists). As a capacitous individual C is, in respect of her own body and mind, sovereign.

98. In circumstances where I have decided that C has at this time the capacity to make the decision in question, this court has no jurisdiction to interfere with the decision making process. Accordingly, although rightly brought, I dismiss the application of the Trust for declarations under the Mental Capacity Act 2005.

Paragraph 99 of the ruling, is as follows:

99. As I said at the conclusion of this hearing, my decision that C has capacity to decide whether or not to accept dialysis does not, and should not prevent her treating doctors from continuing to seek to engage with C in an effort to persuade her of the benefits of receiving life saving treatment in accordance with their duty to C as their

patient. My decision does no more than confirm that in law C is entitled to refuse the treatment offered to her for her benefit by her dedicated treating team. Nothing I have said prevents them from continuing to offer that treatment.

On pages 21 and 22 I considered a ‘position of’ some lawyers, that welfare attorneys can only express a decision ‘at the time it would be put into effect’. That attorneys should not ‘control’ what amounts to ACP around a best-interests decision which would be made by the attorney at some future time, if the attorney were actually present.

I don’t believe, that by his paragraph 99 Mr Justice MacDonald meant to indicate ‘the doctors can seek to **gently** persuade C to let them treat her while she is still capacitous – but then, as soon as she lapses into unconsciousness and becomes incapacitous, the doctors can then treat C against her previously-expressed refusal’. As I wrote on page 22:

Consider a patient in a coma, in hospital, and an attorney who is at the patient's bedside, discussing a life-sustaining treatment such as CANH or artificial ventilation with the clinicians. The attorney tells the clinicians to withdraw the life-sustaining intervention: Essex Chambers do not appear to dispute that the attorney has the power/authority to do this. But, when we apply what Essex Chambers assert about CPR to this scenario, it seems that as soon as the attorney leaves the bedside/hospital, the hospital's clinicians (even the clinicians who the attorney was talking to face-to-face) can simply decide to reinstate the life-sustaining treatments. WITHOUT APPLYING FOR A COURT RULING. If this is how the Act works - then why does it say (section 6(7) and 7.29 in the Code) that clinicians can go against the attorney's decision, and try to keep the patient alive 'while a decision is sought from the court'? If simply waiting until an attorney is no longer physically present, is sufficient 'to remove the attorney's authority', then why bother to put section 6(7) in the Act at all?

I imagine that Mr Justice MacDonald would have been very annoyed, if the hospital doctors had simply waited for C to lapse into unconsciousness, and then decided it would be in her best interests to treat her.

The Conceptual Problem of Incapacity alongside Engagement with Life

I will not spend too long on this – which involves, as an example, people who are living with advanced dementia – but I will discuss it briefly. I show section 4(6) of the MCA on page 6, and a person making a best-interests determination is told to consider the incapacitous person’s ‘past and present wishes’. Unlike the situation of ‘Briggs’, or the situation I discussed in the context of a verbal refusal of CPR

expressed by a capacitous person just before an arrest, ‘incapacitous but engaged with life’ involves ‘present wishes’.

Suppose while capacitous, a person was always grumpy and in general had a ‘negative attitude’ about life. This person creates a series of Advance Decisions which refuse various treatments, including life-sustaining interventions (quick note: it is ‘a series of’ ADRTs because each individual treatment being refused stands apart from each other treatment being refused). Suppose this person develops severe dementia, and as well as what I will here describe as ‘a marked reduction in ‘reasoning skills’ the person has a change of ‘personality’: the incapacitous person living with dementia, seems to very-much ‘enjoy life and being alive’. Does this ‘personality change’, make it unreasonable to apply those ADRTs which were written, in a sense, ‘by a different person’?

I will not attempt to answer that question, and I will simply mention a court ruling by Mr Justice Jackson:

Ref 17 <http://www.bailii.org/ew/cases/EWCOP/2015/60.html>

In it, Mr Justice Jackson ruled that a mentally-incapable patient with a gangrenous foot, who was strongly resistant to its amputation, must not have the operation unless he changed his mind and stopped objecting to the amputation. Without the operation, the patient would inevitably die quite quickly.

Mr Justice Jackson ruled that the operation would not be in the patient's best interests - in other words, that it was in the patient's best interests to allow him to die from his gangrenous foot, instead of allowing the amputation to take place.

Mr Justice Jackson’s words here, strike me as very pertinent and very relevant (my added bolds):

*I am quite sure that it would not be in Mr B's best interests to take away his little remaining independence and dignity in order to replace it with a future for which he understandably has no appetite and which could only be achieved after a traumatic and uncertain struggle **that he and no one else would have to endure**. There is a difference between fighting on someone's behalf and just fighting them. Enforcing treatment in this case would surely be the latter.*

Planning Ahead

There is – quite obviously – much sense in the idea of looking forwards, and trying to predict and if possible ‘plan for’ future developments.

The NHS has something it calls Advance Care Planning (ACP) and also, for ‘emergency’ situations, things which are sometimes called ‘Emergency Treatment Plans’ (ETP). In theory these are two different things: although it appears from some of the evaluation of the ReSPECT form, that some doctors think of ReSPECT as being ACP while other doctors think of ReSPECT as ETP. Personally, I continue to think of the ReSPECT form as unacceptable to welfare attorneys, family-carers and many patients – but, it is an ETP form [and it was called an ‘Emergency Care and Treatment Plan’ before it changed its name to the less-transparent ‘ReSPECT’].

I am loathe to describe many of these things as ‘plans’, and patients can also plan ahead: patients can create Advance Decisions, they can get welfare attorneys appointed, they can explain what they want to happen in conversation with relatives, doctors, family-carers and friends. Patients can also create ‘advance statements’ if they wish to, although in my view a sort of ‘cottage industry’ has grown around the creation of ‘advance statements’ which is not necessarily supported by the MCA. The term advance statement does not even appear in the Act – what appears, is this (my bolds here) in section 4(6):

4(6) He must consider, so far as is reasonably ascertainable—

*(a) the person’s past and present wishes and feelings (and, in particular, **any relevant written statement made by him when he had capacity**),*

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.

I tend to think of those words, as pointing towards in particular anything written [and which doesn’t qualify as an advance decision] which is found after a patient has already lost capacity: it infuriates me, that there seems to be much more emphasis on encouraging capacitous patients to write ‘advance statements’ than there is for patients to create written advance decisions: because what we should all be trying to avoid whenever possible is the often fraught and ‘horrible’ process of best-interests decision-making, and whereas an applicable advance decision **replaces** best interests, an advance statement is necessarily considered **during** best-interests decision-making.

I believe it is helpful to think about the purpose of this ‘planning ahead’, whoever is doing it, and whether for ‘emergency treatment’ or otherwise – and the first step is for the people involved to ask themselves as few questions:

a) What **COULD** I do [if ...]?

b) What **WOULD** I do [if ...]?

c) WHEN would I DECIDE what to do?

And this ‘planning ahead’, will often depend on a capacitous patient being willing to engage with the process, which is not necessarily the case – sometimes, in the context of end-of-life care planning, while a doctor might think ‘the end is getting near’ the patient might simply refuse ‘to discuss dying’. You can replace doctor with family-carer or relative, and patient with loved-one in the previous sentence: in general, I don’t think anybody finds themselves in a very comfortable situation when a person whose death appears to be close, refuses to talk about the future.

The NHS also loves to impose a formal structure on this type of thing – for example ‘MDT meetings’ (multidisciplinary team meetings). As I have pointed out in ref 18:

Ref 18 <https://www.dignityincare.org.uk/Discuss-and-debate/download/325/>

In EoL, sometimes things can happen – clinical deterioration or clinical improvement which wasn't predictable, or a 'clinical development in an unanticipated direction' – which can throw a spanner into 'the best-made plans of mouse or man'.

And **I am going to make an assertion** about the way that decisions are often made during EoL at home:

Often there is no alternative to the decision being made by a group which is a happenstance mixture of patient, family, GP and nurses [depending on who happens to be present] and very often 'common-sense compromises' will be adopted: not 'idealised decision-making' and not 'theoretically-perfect decision-making', but decisions which 'everyone settles for'. It is a case of 'compromising and muddling through' in many situations.

The concept of ‘planning for’ future developments, is of course complicated by the fact that while capacitous, patients can at any time change their mind about acceptance or refusal of a treatment – the Department of Health pointed out years ago, that a capacitous patient can withdraw consent even during a procedure. And, a pregnant woman might have ‘decided’ in advance of the birth to not have pain relief – and during labour, she might change her mind about that.

In principle, if the ‘forward planning’ is made after a patient has already lost capacity, then the planning cannot instantly be rendered null and void by the patient: but, decision-making, whether ‘real-time’ or ‘for the future’ is hugely more complex when we are involved with best interests as opposed to ‘patient autonomy’.

My strongest objection to all of this ‘NHS planning ahead’ is that it invariably involves ‘verification by a clinician’: usually ‘being signed-off by a doctor’. I have

no issue at all, with ‘planning ahead’ which is ‘signed-off by’ a capacitous patient. But this emphasis on ‘the signature of a doctor’ **gives the impression** that ‘the doctors make the decisions’ - which simply isn’t true, if you actually consider the law and reality. These two Twitter Polls, make my point:

https://twitter.com/MikeStone2_EoL/status/931819196207509504

A mentally-capable adult is 'dying' ['end-of-life' = 'sometime within predicted final year of life'] at home. Who should the family-carers living with their dying loved-one be taking instructions from? Please retweet - an analysis of answers would be 'interesting'.

From the dying patient 92%
From the GP and nurses 2%
From nobody 6%

Total votes cast 60

https://twitter.com/MikeStone2_EoL/status/919195401898680321

An 82 years old man is diagnosed as terminal. He and his 79 years old wife ‘invite clinicians to help while he dies’. Does that invitation of itself, imply that if he loses the ability to make his own decisions, he wants the clinicians, and not his wife, to make them?

Yes it does 8%
No it does not 92%

Total votes cast 79

I will not discuss this ‘forward planning’ any further at this point, beyond mentioning that ‘DNACPR documents’ are a part of ‘planning ahead’, and that I will soon be discussing the chaos and contradiction around CPR at some length.

Court Rulings

I have never been very good at finding court rulings, but I have collated various court rulings which I find ‘informative’ in the context of Best Interests in particular in a thread at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/SOME-COURT-CASES-RELEVANT-TO-THE-MENTAL-CAPACITY-ACT-and-to-BEST-INTERESTS-DECISION-MAKING/907/>

Lawyers, of course, pay great attention to court rulings. However, it seems unreasonable for relatives and family-carers, and welfare attorneys, who are involved during End-of-Life (EoL) to be required to become acquainted with court rulings. Consider a welfare attorney, who is appointed when a person/patient is becoming 'end-of-life'. It seems very likely that the attorney, will be a partner or close relative, or close friend, of the 'dying person'. Obviously, the attorney's main concern will be to help their dying [or, sometimes, not dying and in fact recovering] loved-one – spending time studying court rulings, seems to be 'an unreasonable ask'. An attorney is required to 'have regard to' the MCA's Code of Practice, and family-carers might look at the MCA itself. But studying court rulings – well, **not something you should be doing, when your attention should be on trying to help your loved-one.**

This does suggest an interesting hypothetical:

If all patients had appointed welfare attorneys, then bearing in mind the authority given to attorneys to 'control best-interests decision-making', would it not seem logical to ask welfare attorneys (**not** lawyers, or doctors) 'what best interests means'?

I will also add, that during most end-of-life situations, it surely cannot make sense to want to routinely involve courts: we will all die, and the objective should be to try and avoid the involvement of courts if at all possible.

I find the writings of some judges, to be impenetrable and, at times, logically contradictory. More rarely, I come across a judge expressing something with great lucidity – as here, where Mr Justice Hayden explains what 'knowing a person' actually means:

Ref 19 <http://www.bailii.org/ew/cases/EWCOP/2014/4.html>

The patient was in a minimally conscious state and the section of real interest is this one (with my added bolds here):

53. If ever a court heard a holistic account of a man's character, life, talents and priorities it s this court in this case. Each of the witnesses has contributed to the overall picture and I include in that the treating clinicians, whose view of TH seems to me to accord very much with that communicated by his friends. I am left in no doubt at all that TH would wish to determine what remains of his life in his own way not least because that is the strategy he has always both expressed and adopted. I have no doubt that he would wish to leave the hospital and go to the home of his ex-

wife and his mate's Spud and end his days quietly there and with dignity as he sees it. Privacy, personal autonomy and dignity have not only been features of TH's life, they have been the creed by which he has lived it. **He may not have prepared a document that complies with the criteria of section 24, giving advance directions to refuse treatment but he has in so many oblique and tangential ways over so many years communicated his views so uncompromisingly and indeed bluntly that none of his friends are left in any doubt what he would want in his present situation.** I have given this judgment at this stage so that I can record my findings in relation to TH's views. Mr Spencer on behalf of the Trust does not argue against this analysis, he agrees that nobody having listened to the evidence in this case could be in any real doubt what TH would want.

I have always argued that section 4(6) of the MCA allows people who DO KNOW the patient as an individual, to use that 'life experience of the patient' when considering section 4(6).

My co-author Alex Ruck-Keene has written a commentary on a case involving the verbal refusal of a blood transfusion:

Ref 20 <http://www.mentalcapacitylawandpolicy.org.uk/an-oral-advance-decision-to-refuse-life-sustaining-treatment/>

Alex and I do not see eye-to-eye about the verbal refusal of CPR 'during a situation of ongoing contact' - see pages 22 – 24. Part of Alex's comments about the blood transfusion ruling are:

It may be that the judgment is overly compressed in the key part, but on its face it would appear that Peter Jackson J would appear to have accepted that LM's decision to refuse blood transfusion was a binding advance decision notwithstanding the fact that: (a) it related to treatment that must (in the context of her medical condition at the time) be considered life-sustaining; and (b) was made orally, rather than in writing and witnessed, as is required by the terms of s.25(5)-(6) MCA 2005.

...

The approach adopted by Peter Jackson J sits very comfortably with the Supreme Court's emphasis in Aintree upon placing very significant weight upon what could reliably identified to be the views of LM (see also the discussion below of the case of Re X, Y and Z). But by classifying LM's views as determinative and – hence – a de facto advance decision it might be said that Peter Jackson J took one step further than he was permitted by the current state of the law (albeit a step that the Committee on the CRPD would undoubtedly welcome).

I think, that Alex is paying too much attention to something that is beyond dispute (that a verbal refusal of a life-sustaining treatment cannot be a valid advance decision in terms of sections 24 – 26 of the MCA) and not enough attention to the logical consequences of section 25(4)(c). I suspect that Mr Justice Jackson was in fact, using exactly the same reasoning for the blood transfusion, that I use for CPR: that it is very clear what the patient, as expressed while the patient was capacitous, would have wanted if incapacity should intervene - ‘no treatment’. It is ‘dancing on the head of a [legal] pin’ to debate whether we are invoking patient autonomy or what would de facto be ‘**pre-determined** best-interests’ when the patient while capacitous had very obviously considered the situation of looming incapacity and expressed a clear refusal of an intervention in that [anticipated by the patient] situation. I don’t think Mr Justice Jackson ‘*took one step further than he was permitted by the current state of the law*’ - I think he ‘considered the provisions of the MCA **holistically**’. However, I will observe that both of the cases I have quoted from in this section were from 2014, and it was not until the subsequent ‘Briggs’ ruling [and the withdrawal of PD9E] that some of the ‘fog’ was (belatedly!) dispersed around life-sustaining interventions.

Eventually, in the final section of this piece, I hope to make some suggestions as to how the MCA could be presented so that ‘normal people’ will understand its meaning, without ‘dancing on the head of legal pins’.

For now, I will comment that I see the MCA as being ‘the guide to how everyone involved supporting a patient during end-of-life should be behaving – **without** turning to the courts unless unavoidable’.

Uncertainty, Reasonableness and Legality

There is often a serious dearth of knowledge during EoL: in many situations people simply do not know the answers to very significant questions, and when there is knowledge it is often ‘a fuzzy understanding’. Alongside this absence of knowledge there is the fact that sometimes decisions must be made within minutes [or even seconds], so it is easy to see that applying the MCA will be a challenge in some situations.

I think we should, when considering behaviour, use a test of reasonableness. Obviously there is a test of legality – but I think the test of ‘would that be **reasonable?**’ is a more-restrictive test than the test of ‘would that be **legal?**’.

A lawyer once put it to me, that the foundation of the MCA is the protections it provides for professionals. I disagree – I think the foundation of the MCA is personal autonomy during capacity, and the deference towards ‘the person as an individual’ during mental incapacity. But, it is entirely ‘reasonable’ to point out that clinicians are not going to behave in a way which gets them into legal trouble – so doctors and nurses will necessarily seek to behave ‘within the Act’s protections’.

It certainly is not reasonable, to seek to impose on relatives and especially on family-carers, ‘expectations of behaviour’ which in reality essentially reflect ‘what is easiest for the professionals who are involved’. Nor is it ‘reasonable’ to fail to understand that decisions and behaviour are made, and occur, along a timeline.

It is absolutely ‘reasonable’ to rely on a lot of documentation when a patient is in hospital: the staff work in shifts, doctors and nurses each have many patients, and a reliance on verbal information-sharing simply could not work in a hospital. But if a patient is at home, and family-carers are involved, then verbal communication is much more relevant than documentation – at home ‘we talk to each other’. When a 999 paramedic arrives and finds a person in cardiopulmonary arrest, ‘debate about starting CPR’ with any relatives present has to take place in virtually ‘zero time’ - but even the briefest court ruling, allows the judge more time to investigate, consider and decide.

It is reasonable, to apply logic and appropriate previous experience. For example, while the MCA ‘poses the question’ of could a patient in cardiopulmonary arrest be somehow facilitated to make a decision about CPR, any clinician will know the answer is ‘no!’. As CPR is the only intervention which might restore a patient who is in cardiopulmonary arrest to consciousness (including electrical methods within CPR, here), there is no impact of MCA 1(3) in this situation. If you establish that a person is in cardiopulmonary arrest, then ‘without even thinking about it’ you already know, that

1(3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

there are not any ‘practicable steps’ which could allow the person to make a decision [at the time – so discounting an ADRT] about CPR.

There are two sections about ADRTs which make both respecting and also disrespecting an ADRT ‘reasonable’:

26(2) A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment.

26(3) A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment.

I must admit, it isn't clear to me why 'is satisfied' appears in section 26(2), while 'reasonably believes' appears in section 26(3). The issue in question, is whether the reader believes the ADRT to be valid and applicable – and as it happens, I believe 26(2) and 26(3) are 'muddled' and should be in the Code not the Act. However, if as a 'patient' I wrote an ADRT, I would want clinicians to follow its refusal, whereas many 999 paramedics see it as reasonable to want to 'authenticate it':

Ref 21 <http://www.bmj.com/content/356/bmj.j1216/rr-1>

From ref 21:

One place where this can easily be seen, is the issue of cardiopulmonary resuscitation (CPR) when a patient is at home, and a cardiopulmonary arrest (CPA) is not considered likely. Clinicians often imply, in their writing, that in this situation the patient cannot refuse CPR by means of a written Advance Decision (ADRT). This is utter rubbish, logically: I am not expecting that a drunken driver will swerve his car onto the pavement and hit me, but I can certainly think about the likely consequences, if that were to happen. Similarly, I can consider the consequences of an unexpected CPA.

The only thing which does definitely follow from a home CPA being unexpected, is that the GP could not certify the death – but that is an unrelated issue, to whether I can use an ADRT to forbid attempted CPR for a 'sudden CPA'.

If I consider such a 'sudden CPA' and then I write an ADRT refusing CPR for it, I would be doing that in the knowledge that if I were in CPA when 999 paramedics arrived at my home [after, probably, having been called by another person such as a spouse, who had seen me collapse], I would not be conscious – so, I would have written the ADRT with the intention that it should be followed, in exactly that situation (of an unexpected arrest, and when there was no time to look at my ADRT beyond confirming its Prima Facie validity).

Clinicians seem to think, that in this situation – when there is 'an emergency' – my ADRT can be ignored, because there is no time 'to confirm it'. But to the author of such an ADRT, surely that is exactly the opposite of what you would expect – as I wrote in 'ReSPECT is incredibly DISRESPECTFUL':

'An ADRT which appears prima facie valid should be accepted as being valid, if there is not enough time to check in more depth: it is during a non-emergency that the prima facie apparent validity of a written ADRT should be further examined !'

I will now move on, to a discussion of CPR and the chaotic mess that surrounds it, after restating something I wrote earlier:

I think the test of ‘would that be **reasonable?**’ is a more-restrictive test than the test of ‘would that be **legal?**’.

Cardiopulmonary Resuscitation (CPR)

I once described the situation around CPR/DNACPR as resembling a web, which had been woven by several spiders who were not working together, and with some of the spiders being intoxicated.

I think the most striking, and surprising, unsatisfactory belief is the idea that a ‘DNACPR Document’ can be created in advance of a cardiopulmonary arrest (CPA) – I have analysed this in a recent piece which is ref 8:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/435/>

I will ‘correct something’ in that piece, here. I described a meeting to discuss CPR while the patient is unconscious, and I wrote:

Imagine a room in a hospital, with an unconscious patient, and the patient’s consultant, a junior doctor, the nurse in charge of the ward, the patient’s spouse, two brothers of the patient, and three children of the patient all in the room discussing whether or not CPR should be attempted if the patient arrested.

In reality, that discussion would probably not be taking place in the room where the unconscious patient/loved-one is, because there is a belief that some unconscious patients are aware of conversations.

My conclusion about this ‘documentation in advance of a DNACPR ‘decision’’ was stated in this section:

We now get to the ‘legally tricky’ bit. This ‘group of informed individuals’ wants to share its understanding that DNACPR probably should not be attempted, with ‘suddenly-introduced’ clinicians such as a cover hospital doctor at 3am or a 999 paramedic. But the law does not allow for the group to document ‘an order’ (or an ‘instruction’) that CPR should not be attempted. It just cannot be done – and this is why legally-aware clinicians no longer refer to ‘DNACPR Orders’. But, the purpose of the documentation is still to try and prevent ‘comparatively uninformed clinicians’ from attempting CPR – and, much high-level CPR guidance still tends to describe the DNACPR documents as ‘instructions that CPR should not be attempted’. The closest

thing to an order that CPR should not be attempted, is an Advance Decision refusing CPR [and even then, section 25(4)(c) is problematic in practice].

Many doctors, like to stress that CPR is not an appropriate intervention during ‘normal dying’ - with ‘normal dying’ being a situation ‘when the body dies first, and afterwards the heart stops beating’. CPR is indeed useless, in that situation: but, if a near-to-death patient wants to forbid attempts to restart the heart by means of an ADRT, it is still CPR which would be specified as the treatment being refused.

I also come across, a sort of ‘suggestion/implication’ that considering CPR, and considering DNACPR, are somehow two different processes – but it doesn’t matter whether you consider CPR or DNACPR, because either way you end up at either ‘attempt CPR or do not attempt CPR’. I admit, I am always perplexed when I come across this apparent implication that CPR and DNACPR can be considered separately.

The guidance around CPR/DNACPR has always suggested that if a clinician believes CPR could not be clinically-successful, it should not be attempted: and yet, every so often it seems a nurse will be sanctioned by the NMC for failing to attempt CPR when to an outsider it looks as if ‘the nurse didn’t attempt CPR because it appeared the patient was already dead’.

Personally, I have made a suggestion – and it really isn’t ‘a joke’, it is a serious suggestion – that CPR should be attempted if the patient while capacitous requested CPR, even if the clinicians believe CPR could not work:

Ref 22 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mikes-Cheeky-Blog-I-believe-that-CPR-should-be-attempted-if-a-mentally-capable-patient-had-asked-for-CPR-to-be-attempted/1051/>

‘The NHS’ likes to ‘translate’ ADRTs refusing CPR (which are ‘legally binding’ but signed by, and entirely under the control of, a [potential] patient) into ‘DNACPRs’ (which are not legally binding, and are signed by and under the control of clinicians {usually a doctor, but sometimes a nurse}). That has the appearance of madness – why ‘convert’ a legally-binding document into a non-legally-binding document?! Sadly – writing as a former family-carer – the only reason I can see, is that the NHS ‘respects’ the signatures of doctors, even when the doctor isn’t legally ‘in control’. This is one of my ‘tests for change’ of the ‘NHS Mindset’: only when the system prefers ADRTs refusing CPR to ‘DNACPRs’ will I consider that the NHS is respectful of the legal-autonomy of patients.

I have made a suggestion, about how the interface between family-carers and 999 paramedics should work for CPR, in this piece:

Ref 23 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-have-a-suggestion-for-how-family-carers-and-999-paramedics-could-be-reconciled-for-CPR-decision-making-feedback-from-family-carers-welcomed./1031/>

And I have recently published my 'part 2' to the paper in the Journal of Medical Ethics which Zoe Fritz, Rob Cole, Alex Ruck-Keene and I wrote (ref 1), in which I address the implicit question posed by Rob's scenario:

Ref 24 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Clinicians-and-Relatives-Consensus-Uncertainty-Emergency-and-Trust-a-continuation-from-a-Journal-of-Medical-Ethics-paper/1112/>

Instead of explaining what I said in ref 24, I will show some e-mails I have recently exchanged with someone at the College of Paramedics, made possible by my publication of ref 24 – I hope to discuss my concerns with the College of Paramedics after the end-of-year 'break'. I have redacted the identity of the person who I contacted at the College, from the e-mails, and this e-mail exchange took place during October 2021:

From me to the College of Paramedics person:

Hi [redacted] (if this reaches you),

I would like to ask the College of Paramedics/you a question, and I'm guessing at e-mail addresses for you: if I can't find one I'll tweet to you, but my question is 'complex' and I think e-mail might be better,

Regards,

Mike Stone

Reply to me:

Hi Mike

A great guess and yes it worked.

Please send over your questions.

Thanks

Regards,

[redacted]

From me to the College of Paramedics person:

Hi [redacted],

I'm sorry the question isn't simple - but I think unless somehow resolved, it will become increasingly problematic. I don't have the internet at home, and I had it pre-typed as follows, and was about to send it now I'm online in my local library:

Dear [redacted],

I half-heard you speaking on BBC Radio 4 yesterday, and part of the half I did hear was that you were with the College of Paramedics. This prompted me to realise that this might be an opportune time to put a question to the College: please forward this e-mail, to those of your colleagues best-placed to respond to my question, if you would be so kind.

For almost a decade, I have been bothered by an issue with the paramedic-relative interface, but only recently have certain things made it possible for me to describe the issue both clearly and reasonably concisely: these things are the 'Briggs' court ruling, a recent Journal of Medical Ethics paper which I contributed to and a recent Journal of Medical Ethics blog which I wrote, and a very recent PDF which I wrote and which can be downloaded from my Dignity in Care thread at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Clinicians-and-Relatives-Consensus-Uncertainty-Emergency-and-Trust-a-continuation-from-a-Journal-of-Medical-Ethics-paper/1112/>

Please download and read the PDF - URLs to the two JME pieces are within the PDF.

The original version of the Mental Capacity Act's Code of Practice, states (the final sentence of section 5.31) that in the context of best-interests determinations 'Healthcare and social care staff should also refer to relevant professional guidance

when making decisions regarding life-sustaining treatment'. I believe that 'professional guidance' for paramedics, should come from the College of Paramedics. And, for the situations of concern to me, the LST would be CPR.

In a nutshell - it seems unnecessary to go into the detail which my PDF and the JME pieces cover, as you can read them - it is possible to have situations when legally, morally, ethically and logically if summoned 999 paramedics would probably commence CPR, but a family-carer knows that CPR is inappropriate. What the family-carer might be less sure of, is whether their loved-one is actually in cardiopulmonary arrest. I know that 999 paramedics want to help, but I myself am deeply-vexed by the problem I outline: as I state in my PDF, I suspect I would not currently phone 999 in the situations I discuss, because currently I believe that most 999 paramedics would commence, and probably continue, CPR [which I knew to be inappropriate).

Can you tell me, has the College issued any 'professional guidance' which applies to the situation I discuss in my pieces? And if it has, could I see that professional guidance, please? I would LIKE to be able to tell family-carers 'if you phone 999, both your understanding of your loved-one and the paramedic's understanding of the clinical situation will be correctly utilised'. But at the moment, I cannot honestly say that to relatives and family-carers - which is a situation I am less-than-happy-about.

Regards,

Mike Stone

Reply to me:

Dear Mike,

Thanks for a great question- one I have confronted in my clinical practice too so definitely relevant!

I have referred on to colleagues to respond back to you as more appropriately qualified than myself.

Thanks

Regards,

[redacted]

So, it isn't as if the problem(s) which I see/perceive, and which so annoy me from my family-carer perspective, are invisible to clinicians: as the person at the College of Paramedics wrote '*Thanks for a great question- one I have confronted in my clinical practice too so definitely relevant!*'

The problem, is in the 'give and take' - are clinicians and NHS protocol-writers, willing to move far enough in the direction of trusting relatives and family-carers, such that [to use my phrase here] informed-relatives can trust 999 paramedics?

Can the NHS, come to terms with the 'fuzzy knowledge and disseminated decision-making' that an undistorted application of the MCA, situational reality and logic, leads to?:

Ref 25 <http://www.bmj.com/content/358/bmj.j3257/rr-4>

As I pointed out in ref 25:

I have been writing about similar themes within the context of end-of-life for several years. It is definitely true that in 'this internet age' laymen can relatively easily discover what the professionals are writing and doing, whereas previously it was virtually impossible to acquire that knowledge. The NHS uses the internet and similar systems for a different purpose, of recording and disseminating information about individual patients, and the NHS still clings to 'paternalism': for example, the recently-developed 'ReSPECT' persists in placing the clinician 'front-and-centre for the decision-making' (1). I have pointed out more than once, the issue which Fiona Godlee describes as 'most challenging of all, shared accountability (replacing medical authority with mutual trust)' (2).

This is a deeply difficult transition for 'the NHS' to come to terms with: because to a significant extent, 'shared' equals 'diffuse', and 'diffuse' means that things such as clarity of decision-maker, hierarchy and 'easy descriptions of decisions' are no longer available. Which means, of course, that they cannot be easily recorded on those 'electronic databases' so beloved of NHS policy creators.

It is easy to see 'where we need to get to' if you study recent laws such as the Mental Capacity Act, and recent court rulings, which place the stress on 'the individuality and autonomy of the patient', but it is much less easy to argue that real-world clinical and NHS behaviour will reach that destination any time soon.

1) <http://www.bmj.com/content/356/bmj.j876/rr-7>

2) <http://www.bmj.com/content/350/bmj.h3181/rr-2>

I think, it is now time for me to try and suggest how we could ‘teach’ the MCA, in line with what was stated (in a line I’m fairly sure Zoe wrote) at the end of our JME paper:

The guidance and the training should emphasise the tea[m]work which Mike Stone mentions above: the default assumption should be that clinicians and relatives have a shared goal of what is best for the patient, and work together as ‘us and us’ as opposed to ‘us and them’.

I will briefly digress, to show the views of another person about ReSPECT forms (this must have involved an earlier version of the form, than the recently-revised version).

A Couple of Comments on the ReSPECT Form

I dislike the presence of only clinical-signatures on the ReSPECT form, within its more-important sections – but I am not trying to exclude the signatures of doctors. My position was clearly stated in a BMJ rapid response I wrote a few years ago:

Ref 26 <http://www.bmj.com/content/352/bmj.i26/rr-5>

In this series of responses, Jay Ilangaratne has provided links to the Tracey and Winspear rulings, and Richard Venn has commented that 'Ongoing dialogue around 'Emergency Care and Treatment Plan' is a start in the right direction'.

The Resuscitation Council UK is currently hosting a consultation about a proposed 'universal' ECTP (ref 1). I dislike many features of the 'prototype' ECTP, for example that a patient can only be either 'FOR CPR' or 'NOT FOR CPR': it is very clear, from considerations of consent law or from the Mental Capacity Act's description of Advance Decisions, that a patient's refusal or acceptance of CPR [or a CPR best-interests decision] could be conditional - it can be 'CPR should not be attempted unless 'specified conditionality"' (although it is 'technically' very difficult to write an ADRT refusing CPR with that structure - you can apparently {see MCA 25(4)(b)} only write 'I refuse CPR if 'specified conditionality"'). It is equally clear that if there is a suitably-empowered welfare attorney, best-interests CPR decision-making falls to the attorney [and not to anybody else {MCA 6(6) and 6(7), and MCA Code of Practice 7.29}] if CPR might be clinically successful (and I do not consider 'we will not offer CPR, because in our expert opinion CPR could not be successful in restarting the heart' as being a 'best-interests decision': it doesn't seem to be a decision at all, if the prediction is correct, because the outcome is death with or without CPR). The ECTP prototype also mentions shared decision making, which I greatly dislike as a phrase (ref 2).

The recent ruling by Mr Justice MacDonald (see ref 3) has made it clear that mentally-capable patients make their own decisions, which are not then to be questioned by others, and I have pointed out above that sometimes it is legally clear that a welfare attorney [or, but never for CPR, a court deputy] is the decision maker. The Winspear ruling starts its point 4 with 'Although the precise terms of that conversation are a matter of dispute,' and exactly who said what during Tracey, is very uncertain indeed. The ECTP prototype does mention conversations between clinicians, patients and relatives - but it does not suggest that such records of conversations, should be 'signed off' by 'all sides': the ECTP wants only clinicians to sign. Similarly, the ECTP does not seem to want attorneys and deputies to sign to confirm their decisions - again, it wants the clinicians to do the 'signing off'. This is both legally dubious - people should sign for whatever they are responsible for, so a clinician signs for a clinical prediction, a welfare attorney signs to 'authenticate' his/her own best-interests decision, etc - and anachronistic. This type of 'clinical control' of 'patient records' reinforces inappropriate distinctions between clinicians and involved laymen, it potentially introduces 'bias', and it definitely does not promote the necessary cooperation and integration between the clinicians, family, friends, and if they are present attorneys and deputies, which decent 'joined-up' care requires.

Once, husbands 'owned their wives' - but no longer: and clinicians do not 'own their patients'. Until patient records contain within them the 'right' signatures (at the very least, the possibility of the right signatures being present: I accept that it might be difficult for patients and family members to sign such documents, but they should definitely not be prohibited from signing them) - signatures based on authority, responsibility and involvement, and not simply on whoever happens to be 'the senior clinician' - there will in my opinion never be satisfactory integration between the many people who are typically involved in supporting, and caring for, patients.

The complexity of best-interests decision-making, and my mother's death (see ref 4), convince me that we should be pushing for patient-expressed decisions made in advance: so it is Advance Decisions which need to be promoted. But there seems to be an agenda to encourage patients to create 'written advance statements', which - unlike a written advance decision - cannot 'just be followed in an emergency'. In contrast to this push to promote the essentially 'very challenging in application' 'written advance statement', nobody seems to be trying to address the problem I mentioned in reference 5 of a patient at home expressing a decision to only a family carer.

I am not reluctant to state, and the perceptive reader might have discerned this, that I am very annoyed by this situation.

Some years ago, I was contacted by someone who had been very upset by a nurse who visited his father's home, and completed a ReSPECT form which it seems did

not reflect his father's positions. And, it seems his dad was getting very upset during the conversation with the nurse, who nevertheless continued the conversation despite the person becoming distressed. This Christmas, I received the following e-mail – note that this person wanted CPR to be attempted [so it is not like many of my scenarios when a relative wants CPR to be withheld]:

Hi Mike,

When dad went, the first responder was with us within minutes. She asked me if dad had a ReSpect form to which I replied no, but that I recently had a 'ReSpect' style conversation with him and that he wanted to be revived. She asked me why he didn't have one and I gave a brief recap of the issues we had with the nurse who tried to conduct the ReSpect interview. The first responder then said she preferred to have one because if there are two relatives present (theoretically speaking as I was on my own caring for dad) then two relatives could (theoretically) have different wishes i.e. one could want their relative revived (or at least an attempt made) and the other not. However, she was missing the point that the original respect form was effectively written with the nurse's wishes for my dad and not his own and nor could they have been his own wishes.

The first responder seemed to be blinded to the concept that their patient may not have had mental capacity to agree to the form or that the form might not have been the patient's wishes. There seemed to be a worrying belief in what appears on the form to be absolutely true (without any knowledge or interest in) the process by which the form was completed.

I always thought the 'mantra' of health care professionals was 'first do no harm'! The ReSpect process as it stands has very obvious concerns regarding how the interviews are conducted and particularly to mental capacity to understand or consent to what the nurse conducting the interview is suggesting. The lack of a signature by a senior doctor or consultant is especially troubling as this takes away an avenue by which the mental capacity of the patient to consent to the form can be questioned.

I hope this helps.

You have consent to quote me and or make edits.

Best Regards,

[redacted]

As it happens, I am now of the view that 'fixating on' the admittedly very-important issue of mental capacity, can lead people down some very narrow and twisting country lanes and I don't think a doctor's signature resolves that (bluntly, if a GP and

a relative both agree that the patient/loved-one is ‘clearly incapacitous’ then what matters is the consensus – but if the GP and relative disagree about whether a patient/loved-one is capacitous, the signature of the GP doesn’t resolve anything).

I decided to show the e-mail, to illustrate that different people have different concerns about the ReSPECT form. I share some of the concerns expressed by the person in that e-mail, and I will point out that I’ve covered relatives disagreeing about CPR in ref 23. I seem to recall, that the person who sent me the e-mail had mentioned to me that his elderly father was also a bit deaf, and could well have been ‘nodding along’ as the nurse talked to him without properly following what was being said – probably a good reason to ‘interview’ elderly patients in the presence of someone who knows the person.

How the MCA could be described (or taught)

I will now make some suggestions, as to how I think the Mental Capacity Act could be explained to people who ‘work with’ the MCA but who are not expected to be ‘experts in the Act’, and also to relatives, family-carers and others. My suggestions, are an attempt to describe how we might impart a better-understanding than is currently widespread – I am not attempting to cover ‘all the caveats’ nor to cover very complicated situations: but, in very complicated situations, ‘an expert should be called in’.

I think we need to start, by making it clear that mentally-capable patients make their own decisions, even if those decisions are ‘self destructive’ or unwise – and I believe we need to state that in most situations a person will be mentally capable if the person appears to understand the consequences of a decision. So in the medical context, a patient who seems to understand the consequences of accepting or refusing an offered treatment, is probably [in the context of that treatment] mentally capable. We should also avoid saying ‘a capacitous person decides in her own best interests’ and instead say ‘a capacitous person, once informed, makes her own decision’. See ref 16 on page 25 for the application of this ‘approach’ by Mr Justice MacDonald.

We should also be clear, that the MCA does not explain whether or not a treatment should be offered. Treatments should be offered if they might be clinically-beneficial (i.e. if the treatment ‘works’) and if the NHS can afford to offer the treatment. The NHS has to be ‘fair to all’ so it cannot afford to offer some effective but very expensive treatments – and in such a situation, an individual clinician is not deciding to withhold the treatment so it isn’t ‘the doctor decides what to offer’. Sometimes I come across the phrase ‘clinical best interests’ and I dislike this phrase: it should be replaced with terms which are closer to ‘clinically effective’ as a description of which treatments should be offered. Similarly, I have always disliked ‘futile’ as a description

of why a treatment will not be offered: ‘if the treatment would not work’ is clearer than ‘if the treatment would be futile’ in my opinion.

We should also ‘teach’ that almost always, it should be of no consequence whether a patient is capacitous or incapacitous, when it is being decided which treatment/s should be offered.

So, moving on to incapacity. First, stress that it is always capacity or incapacity for a particular decision and at a specific time. Second, stress that normally the presence or absence of capacity ‘will be ‘obvious’’: and, if it isn’t obvious, then at that point ‘harder thinking’ and perhaps the calling-in of an expert are appropriate. If a GP and the patient’s partner both believe the patient is incapacitous (or capacitous) then in my view they are likely to be correct – but if the GP and the partner disagree, then I think the situation is much more complicated.

We also need to point out, that except for situations akin to that of the Briggs ruling, when for practical purposes Best Interests collapses to Substituted Judgement with a fall-back preservation-of-life position if we cannot be sufficiently certain of what the individual would have decided, there is not a clear way of describing best interests. And I don’t mean what would amount to ‘clinicians are better-equipped to make best-interests determinations because they have studied the MCA in greater depth’: I mean ‘... it isn’t a case of the clinicians ‘possessing expert knowledge about best interests’ - because there ISN’T ‘expert knowledge’.

What we do know – **and which should be [repeatedly!] stressed** – is that the MCA moved from emphasising ‘the average patient and the average patient’s ‘choices’ to the now-current legal approach based on emphasising ‘the patient as an individual, both while capacitous and while incapacitous’. As I wrote in the JME paper:

‘Put simply, the clinicians are the experts in the clinical aspects, and the family and friends are the experts in ‘the patient as an individual’.’

And it should then follow, that we need to use the expertise of both clinicians and relatives and friends – also from the paper:

‘And, the direction of change must be one which improves the support given to patients, by promoting integration between everyone, lay and professional, involved in supporting patients. This ‘model’ requires ‘us and us’ as opposed to ‘us and them’: it emphasises teamwork between family carers and the clinicians who are in regular and ongoing contact with the patient, and it replaces ‘multidisciplinary team thinking’, with genuine professional-lay integration.

Anyone can listen to a patient—provided you are present to listen: if only a relative is present, only the relative can listen. Often it will require a clinician, such as a 999 paramedic, to confirm that a patient is in cardiopulmonary arrest, but the family

carer who called 999, is the person most likely to know if the patient would have wanted CPR.'

The MCA uses the word 'reasonably' in places, and real-world application of the Act should involve the concept of 'is that reasonable?'. We could stress sections 6(6) and 6(7) when explaining the authority of a welfare attorney: or, we could mention section 6(7), and also add '... however, before you over-ride an attorney's best-interests decision and apply for a court ruling, remember that the patient wanted the attorney to make the decision'. We could view Advance Care Planning and other records through a very optimistic lens of 'surely the records will be accurate and up-to-date' - or, through the more realistic lens of 'recent events will probably have not found their way into documentation – which doesn't mean those events did not happen'.

Professionals could reasonably stop 'going beyond the Act' and writing 'guidance' which merely makes life simpler for them. For example, it isn't reasonable to assert (and I do come across this assertion – certainly, I used to come across it) that close relatives cannot witness a written Advance Decision – that isn't reasonable because it isn't present in the Act:

(From a lawyer when I mentioned this issue of the Act simply requiring a witness, but various professionals 'claiming' a close relative cannot be the witness in 'guidance')

From me to the lawyer:

Yes, in a sense re rabbit hole.

You have not yet told me whether you tell protocol writers that any person over 18 can witness an ADRT? If policies said that R can witness an ADRT, even if R is a spouse, child or family-carer, then I would tend to spend less time going down rabbit holes! It is hugely problematic adopting an approach of 'explain the MCA without getting all legally nerdy' when at some point lawyers (not pointing any fingers here - but you are a lawyer!) will get legally nerdy when talking to HCPs! It is a problem I have not yet resolved (and, getting nerdy, section 42 makes it legally impossible to 'advise' most relatives - despite that the BMA etc does keep 'stating what the law means' in its material for patients and families).

From the lawyer to me:

Witnessing of ADRTs is an area of real difficulty. The Act is silent as to witnesses (except that you need to have one), and the current Code doesn't say anything either way about who can do it. It is a bit like the situation with contemporaneous assessment of capacity to make the ADRT, which doesn't feature in the Act or the Code. But given the deep distrust that still exists amongst many about ADRTs, and the fact that they can be 'broken' and not considered to be binding if they are

found to be invalid/not applicable, my view is that it's always sensible for the person completing the ADRT to think about how best to insure that they are binding. Choosing someone as a witness who has a personal connection always and inevitably (even if it shouldn't) opens the door to someone who wants not to follow the ADRT to challenge the role of the witness (for instance that they might have coerced the person into signing).

So, my view is that you can always stick to the letter of the law and have anyone you want (because the Act says so) but that you should be aware that if you do then you are potentially opening the way to a problem later, at a point where (by definition) you won't be in a position to do anything about it.

I think, if time allows (and sometimes it wouldn't – in my Father and Son scenario*, even if they knew about ADRTs and the father wanted to create one, who except the son could witness it: are you expected to 'drag a witness in off the street' at 9pm of an evening?!), it would be useful to add subsequent 'witness' signatures to ADRTs anyway. If created by a patient who asked a relative or friend to initially witness it, subsequently as events allowed to add the signature of a GP or District Nurse – and, if an ADRT were created in hospital and witnessed by a clinician, as events allowed the signatures of family-carers could be added.

* 'Father and Son' is already sub-referenced, but it can be found directly at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/298/>

Unless 'informed family-carers' can feel confident that 'the NHS will believe them', I don't think those family-carers can confidently phone 999 with an expectation that decision-making will correctly combine their 'expert understanding of the patient, and likely-situation 'of being the most-recent listener [to the patient]' and the clinical expertise of attending 999 paramedics. Relatives cannot be confident, of the answer to what I wrote on page 42:

The problem, is in the 'give and take' - are clinicians and NHS protocol-writers, willing to move far enough in the direction of trusting relatives and family-carers, such that [to use my phrase here] informed-relatives can trust 999 paramedics?

Can the NHS, come to terms with the 'fuzzy knowledge and disseminated decision-making' that an undistorted application of the MCA, situational reality and logic, leads to?

I myself, will not believe this change has happened, until I see different signatures on things such as the ReSPECT form – see ref 26 on page 43. In particular, I will only believe this change has happened when 'signatures based on authority, responsibility and involvement, and not simply on whoever happens to be 'the senior clinician' can

be observed on ‘the NHS’s documents’. I admit, this introduces complexity around ‘ownership of’ such a form (different sections of the form, would be ‘owned by’ different individuals – but surely that is a consequence of a genuinely collaborative approach?).

Documents should stress ‘who has been involved, to what degree have individuals been involved, who has been in ongoing conversation with who, etc’ **much more than** ‘who is the senior clinician’. And, partly as there is ‘history of’ clinicians being quite poor at the ‘talking to family and friends’ aspect, we certainly should not have records/descriptions of such conversations being recorded and signed-off by only the clinicians: both parties to a conversation should have the opportunity to read and ‘sign-off’ a record of a conversation, whoever wrote the record.

And it is always ‘unreasonable’ to expect anyone to prove the unprovable: no paramedic should ever expect a family-carer, standing next to a now-collapsed loved-one, to ‘prove’ that a conversation had taken place a few hours previously if the family-carer says it took place.

On page 45 we can read this – presented ‘as a problem’ (and it is a ReSPECT form which she ‘prefers to have’):

The first responder then said she preferred to have one because if there are two relatives present (theoretically speaking as I was on my own caring for dad) then two relatives could (theoretically) have different wishes i.e. one could want their relative revived (or at least an attempt made) and the other not.

From my family-carer perspective, the closing of the above - ‘but relatives might disagree’ - is a legitimate thing to consider. Although it isn’t about what the individual relatives ‘want’ - it is about what different relatives believe their loved-one would want. And, while I’m sure it might lead to subsequent arguments within the family, if for example two daughters are in disagreement about ‘what dad would want’ then I see them as each in theory speaking from **informed** positions. And, in that situation the clinician must adopt ‘preservation of life’ - because the clinician does not know the patient as an individual, **so the clinician cannot have** an ‘informed position’ [acquired directly from the patient] as to what the patient would want to happen. And, it is deeply unreasonable (and this does seem to me to be implied by the ReSPECT form) to suggest that ‘the clinician makes a decision which fundamentally depends on understanding the patient as an individual’ - I would probably be ‘vexed by’ a sibling who was expressing a contrary view about ‘what dad would want’, but I would be **ruddy furious** with any emergency clinician who said ‘I understand what your dad would want, better than you understand what your dad would want’. I am also ‘ruddy furious’ with ‘the attitude’ that it is legitimate to heap-on-top-of the distress of caring for a dying loved-one, ‘... and the system doesn’t trust you’.

Everyone needs to stop writing obvious nonsense, such as ‘only a senior clinician can make a DNACPR decision’. Only an expert clinician can make a competent prediction that a future cardiopulmonary resuscitation attempt ‘could not be successful’, but even then that is not a DNACPR decision (it is a possible justification for withholding CPR – but, see ref 22). And when pressed, most doctors would admit that in most situations they could only honestly say ‘CPR almost certainly wouldn’t work’ - not ‘CPR definitely wouldn’t work’.

So, here is my attempt to describe Informed Consent and MCA Best Interests, in a concise and ‘usually correct’ way, in the context of medical treatments and in England or Wales:

If a patient seems to be able to understand the consequences of his or her decision, then the patient is probably mentally-capable. In which case, the role of a clinician is to inform the patient of the clinical consequences of accepting or refusing an offered treatment, after which the patient decides whether to accept or refuse.

If it is clear that a patient does not possess mental capacity for a particular decision, then decisions should be made in the patient’s best interests as required by the Mental Capacity Act. Best Interests always requires an attempt to be made to work out what the patient would have decided if the patient had been capacitous - a concept usually called substituted judgement. For treatments which are NOT life-sustaining, if it is understood what the patient would have decided if capacitous, then best interests can depart from ‘what the patient would have decided’ but explaining precisely how and why is ‘fuzzy’: the simplest way to think about it, is perhaps to say that a capacitous person is entitled to make ‘a bad decision’ but a best-interests decision-maker is expected to make ‘a good decision’ which gives the incapacitous person the ‘best’, when seen from the incapacitous person’s ‘future perspective’, future. For some situations which involve an incapacitous person and a life-sustaining treatment, best interests DOES become substituted judgement: if it is understood with sufficient certainty that the patient would, if capacitous, have refused a life-sustaining treatment then the treatment should be withheld or withdrawn.

If a Welfare Attorney or Court Deputy has been appointed, then that person’s role is to make best interests decisions which are within the scope of their authority, so clinicians should be providing information to help attorneys and deputies to make the best interests decisions.

If a valid and applicable Advance Decision has been made by the patient, then the decision removes the need for any best-interests decision-making to take place: indeed, best interests cannot legitimately occur if an ADRT is valid and applicable for the intervention being considered.

More pragmatically if ‘those close-to the patient’ and the clinicians involved openly and collaboratively get their heads together and all agree about what would be best for an incapacitous patient, then what they have agreed upon probably is a good best interests decision.

So when a patient is incapacitous, clinicians and the people who know the patient as an individual - especially family-carers - must work together to determine what is in the patient’s best interests. Family-carers in particular are not ‘passive observers’, and family-carers, relatives and friends who know the patient as an individual are ‘experts in the patient as an individual’, and clinicians must accept and respect that in the same way that lay people must accept that clinicians are experts in clinical things. Clinicians and ‘relatives’ **MUST WORK TOGETHER** and need to start from a position of **TRUSTING EACH OTHER**.

Written by Mike Stone, January 2022 – and I know that my description above of how Best Interests departs from Substituted Judgement is imperfect and rather obtuse: I invite others to do better [and I would be very pleased indeed, if somebody could clearly-describe MCA Best Interests].

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